


# Understanding life experiences of people affected by Crohn's disease in Spain. A phenomenological approach

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## Understanding life experiences of people affected by Crohn's disease in Spain. A phenomenological approach

**Background and objectives:** People affected by Crohn's disease must adapt their lives to their new chronic condition, and therefore, understanding such experience can be helpful in planning effective interventions for the affected ones. The aim of this study was to gain an insight into such experience and how they adapted in different areas of their lives, particularly in a family-centred culture such as the Spanish one.

**Method:** A descriptive phenomenological study was conducted through in-depth interviews to 19 people diagnosed of Crohn's disease in the province of Alicante (Spain). Once the interviews were transcribed, data were analysed using Colaizzi's seven-step method.

**Results:** Five emergent themes were identified: self-protection against the unknown cause; self-training;

learning to live with Crohn's disease; perceived losses associated to Crohn's disease; and relationship with others. The results portrayed a chronically ill patient who is unconscious about the chronicity and consequently must develop strategies to keep living a similar life like the one lived before.

**Conclusions:** This study revealed that people affected by Crohn's disease struggle with the fact of being a chronic patient with uncertainty about the illness and need to learn living with a chronic condition that limits their daily lives. Furthermore, the lack of Crohn's disease a professional in charge of these people's Cares such as the specific nursing role existing in other countries support in the Spanish Health System determines the loneliness those diagnosed experience to cope with the new situation.

**Keywords:** Crohn's disease, nurse, social support, life experience, phenomenology.

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## Introduction

Crohn's disease (CD) is an inflammatory bowel disease. It can affect any part of the intestine, although the ileum is the most common site of involvement. It is characterised by insidious onset in young people and by periods of remission and flare-ups (1). Recent studies have suggested that the prevalence of the disease will increase worldwide (2).

The behaviour of CD at a physical and pathological level is mostly known nowadays, as are the different forms of treatment to mitigate its effects. In fact, this is the subject of most published studies (3–5). Nevertheless,

the impact of this disease on the lives of those affected and its psychological and emotional effects are fortunately receiving increasing research attention (6–9). When one receives the diagnosis of a chronic disease, and more specifically of CD, one wonders not only about the physical consequences, but also about how the disease will affect one's life (10) and its surroundings, and consequently, the social support received from that moment will be a very important factor to keep in mind throughout the illness ongoing (11).

Despite the symptom control, the professional treatment of patients with Crohn's disease should include monitoring the difficulties and situations they must overcome in their daily lives (12). Generating scientific knowledge about the life experiences and social support of those affected by Crohn's disease can help health professionals adopt a more holistic approach to their work with these patients, taking into account patient subjectivity and their perceptions about the problem (13).

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Particularly in Spain, several studies have shown the interest of this kind of proposals towards care improvement from a holistic perspective, focusing on implementing specialised units for those affected by CD (14, 15). Few studies have focused on the life experiences and coping abilities from the perspective of those who have an inflammatory bowel disease (IBD). As such, exploring the lived experiences of people diagnosed with CD would provide information for other individuals affected by these conditions and individuals treating patients with IBD disorders (2, 16).

Qualitative methodology is suitable to understand the meaning of living with a chronic disease such as CD as it deals with the meanings, reasons, beliefs, values and attitudes, which correspond to a deeper level of a currently unseen disease in societies (17, 18). Moreover, by exploring the experience of people affected by CD throughout qualitative methods, those needs to be improved in the health-care systems potentially could be highlighted and consequently professional teams could provide the necessary support to the patients offering the adequate care (19, 20).

## The study

### *Aim*

The aim of this study was to describe the life experiences of people with CD towards understanding the changes they must face daily since they were diagnosed.

## Methods

A phenomenological approach focusing on the life experiences perceived by those affected was conducted (21, 22) through in-depth interviews. This method aims to capture, describe and understand the intent of research subjects and the meaning of their experiences in their specific situation, what is adequate for this study purpose (23). It was therefore considered as the most appropriate method to provide CD people with a voice to express what they really live every day.

The study sample consisted of 19 people with a definitive diagnosis of CD received more than 1 year ago and included males and females aged over 18 years living in the province of Alicante (Spain) on the Mediterranean Coast. Subjects were selected according to the 'snowball' method, achieving maximum variance sampling. Researchers used a small pool of initial informants to nominate, through their social networks, other participants who met the eligibility criteria and could potentially contribute to sample diversity. None of the subjects refused to participate in the interviews; on the contrary, they were much eager to talk about their own experience (18).

Data were collected by means of the 19 in-depth interviews conducted between January and April 2014 by a trained early-stage researcher with previous experience in this type of technique. Once participants had been selected, a member of the research team contacted them by telephone to explain the characteristics of the study and invited them to participate. An appointment was then arranged with those who agreed to participate. Data saturation was achieved after the 19 interviews as no additional data were found to develop new properties of themes and the relationships between the themes were disentangled. Researchers saw in their data similar instances over and over again and that made them confident that their categories were saturated. The interviews were conducted at participants' homes according to their own willing to facilitate an atmosphere of intimacy where they felt comfortable. Participants also chose the best time of the day for them to be interviewed, which lasted approximately 50 minutes.

In qualitative research, validity depends on the systematic process of obtaining and analysing data (17). All interviews were conducted by the principal investigator (SGS), thus guaranteeing data consistency and interviewees' privacy. The interviews were recorded on an audio device and transcribed verbatim. The key topics that participants were asked about during the interviews were as follows: (i) own life experience with chronic illness (CD), (ii) changes in lifestyle and (iii) past, present and future thoughts. All the interviews started with an open question about the meaning of being diagnosed of CD. Data were analysed using Colaizzi's seven-step method (24) to provide assistance in extracting, organising and analysing such narrative data set. Softwares for qualitative analysis were not used, as the research team's preference was to develop the analysis through the traditional way. A number of significant statements were primarily identified, then formulated meanings were agreed, and later, theme clusters were integrated to formulate the emergent themes which described the phenomenon thoroughly (Table 1).

The interviews were transcribed and shown to participants for them to corroborate the accuracy of the transcripts. These were analysed by the study authors, who maintained telephone and email contact and met on three occasions to discuss and reach consensus agreement on the information, thus facilitating triangulation of the various data. Later, the team refined and agreed on the most important data that gave meaning to the 12 theme clusters extracted to finally determine the thematic map made of five emergent themes. Narrative accounts (in italics) have been included in this paper to illustrate the various themes.

All participants after expressing interest in participating received a written informed consent document detailing the nature of their participation and the study objectives in general. They were also informed that participation was voluntary and confidential and that they had the right to

**Table 1** Colaizzi's Analysis Method applied to data collected through this study

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*Step 1:* Transcripts of the interviews were read and re-read in order to obtain a general sense in the light of experience. Each transcript was read by at least three members of the research team

*Step 2:* Significant statements and key words were extracted, generating formulated meanings pertaining to the life experience of people with CD

*Step 3:* The four researchers and authors discussed on the different meanings formulated in order to reach consensus on them. At this stage, SGS compiled a list of meanings with the first 16 transcripts. By the analysis of interview 11, the meanings identified became recurrent; nevertheless, the research team agreed to analyse other five interviews more in order to ensure that no new meanings emerged. This indicates that data saturation was obtained by interview number 11

*Step 4:* The formulated meanings based on significant statements were grouped into 12 theme clusters that determined five emergent themes

*Step 5:* All the resulting ideas yielded a detailed vision of the life experience of people with CD. The research team agreed on the cluster and themes

*Step 6:* This document was reviewed by all the team members, who contributed with their comments and thoughts, with the aim of creating a first draft of the analysis. This led to a reduced synthesis while preserving the essence of the data

*Step 7:* The research team read the final summary of the data and compared this with the original transcripts, to validate the results of the study. This step ensured that the data had been suitably processed and represented

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abandon the study whenever they wanted. In relation to the sample characteristics, seven of the 19 interviewees were male and 12 female, with their ages ranging from 25 to 83 years (Table 2). Moreover, this study was approved by the Ethics Committee of the Research Office at the University of Alicante file number: UA-2016-06-20.

## Results

Five emergent themes and 12 theme clusters came up after data analysis (Table 3).

### *Theme 1. Self-protection against the unknown cause*

*CD management.* Since the time of their diagnosis, the participants had never received clear, reliable information. This created uncertainty and resulted in a constant quest for knowledge: *C03 'I have never clearly been told why I have the disease, and although I have often asked... no-one has been able to give me an explanation',* which was also prompted by the variety of treatments: *C06 'I have been prescribed everything but nothing works for me'.*

Since the diagnosis on, as participants kept discovering every day more about their disease, gathering more

information and beginning to learn how their condition functioned, they developed self-protection mechanisms. Some believed that a genetic component was responsible for the onset of their condition, while others thought that CD had been triggered by their previous lifestyle, or that it was necessary to control their emotional situation and avoid stress so as not to worsen their illness: *C10 'I suffer from stress, which I try to control'; C01 'I wasn't used to eat well, I used to party a lot and didn't rest well very often, and that's why I got CD, but I'm more into healthy life nowadays'.*

*Lack of confidence in the health system.* This idea of self-protection was accompanied by an open distrust on the health system. Participants did not trust the professionals treating them, and had lost all faith in them because they were unable to offer useful solutions. This attitude was reinforced by the fact that the health professionals involved in the process from the outset either did not know or were not entirely clear about the characteristics of CD. Participants underwent treatments, invasive tests and other interventions, but still continued to experience symptoms that diminished their quality of life: *C01 'I have to look after myself, because the physicians and other professionals don't help me at all, they're only good for changing my pills and I'm always ill, so now I try to find out by myself what's good for me'.*

### *Theme 2. Self-training*

*Cause-effect.* Participants were self-trained, having learnt from their own experiences and discoveries acquired through constant trials and errors since their diagnosis was communicated (obviously motivated by the lack of clear information): *C15 'I've tried different things out, and now I know what makes me ill'.* Consequently, participants had reached the point where they knew exactly what was good for them, did what they knew from experience worked for them and tended to try what others with similar experience had tried before: *C02 'I was talking with a friend who also has the same situation and she told me that when she went out with friends and didn't know if there was a toilet nearby, what she did was not to eat, so that she wouldn't want to go to the bathroom, so that's what I do too'.*

*Self-control.* Interviewees referred several times to specific control strategies they applied in concrete moments to cope with new situations regarding CD. Participants had become experts on their condition, acquiring knowledge since their diagnosis and throughout the course of their chronic condition: *C02 'I have to regulate how much energy I use, like, if I have to work then I'm more tired when I get home, but since I know this, I try to rest before leaving home'.* Such was their awareness and knowledge about their condition that even when they did something they knew

**Table 2** Sociodemographic data

Code	Age at diagnosis	Sex	Years since diagnosis	Number of Surgical Interventions related	Type of ostomy		Marital Status	Number of sons/daughters
					Temporary (time)	Permanent		
01	31	M	4	0			Single	0
02	18	M	17	2	6 months		In a relationship	1
03	33	F	21	3	3 months	Yes	In a relationship	1
04	19	F	36	1			Single	0
05	20	F	6	2			In a relationship	1
06	18	M	38	3	6 months		In a relationship	2
07	22	M	5	1			In a relationship	0
08	14	F	18	1			In a relationship	0
09	28	F	3	1			In a relationship	1
10	27	M	36	2			In a relationship	1
11	21	F	15	1			In a relationship	0
12	20	F	12	4		Yes	Single	0
13	16	F	21	3		Yes	In a relationship	2 (adopted)
14	27	F	5	2			In a relationship	1
15	18	F	12	0			Single	0
16	26	F	13	1			In a relationship	0
17	14	M	9	0			In a relationship	0
18	48	M	16	1			Single	0
19	13	F	70	0			Widow	5

was harmful, they were aware of it but did it anyway: C01 'Overeating, fast food and spirits are all bad for me, but obviously I don't care when I'm at a wedding celebration or something like that, I eat and drink what I want, even though I know that I'll be worse the next day'. They had also learnt to ration their energy in order to cope with the fatigue provoked by their condition and be able to perform tasks they considered essential for their lives.

### Theme 3. Learning to live with CD

*Normalisation of the condition.* Participants transformed their chronic condition into a natural part of their lives, downplaying their symptoms meaning that the new situation had been integrated into the person's daily life and became part of it. An adaptation process took place, and therefore, the condition was part of their lives since then: C03 'It only hurts sometimes, it doesn't stop me from living a normal life'; C17 'I know I'm a little more tired than others, but I work equally hard'. They did not see themselves as ill and indeed showed great struggling spirit and adopted a positive outlook: C19 'I have always been very positive, I always just get on with things'.

*Ignoring chronic illness.* Participants reported ignoring their illness when not suffering a flare-up, downplaying and normalising any symptoms they might have. This theme cluster was understood as a person's coping strategy though it did not mean there was any adaptation or normalisation process. They said they were

convinced that thinking about their condition aggravated and intensified their symptoms: C05 'I don't think about what I've got because you'd just become bitter, so I live as though I didn't have it because I think quite enough about it when I have a flare-up'; C08 'I don't even speak about Crohn's with others, because the more you think about it, it's as if you were summoning it and you have a flare-up'.

*Expertise management.* Interviewees evidenced such extensive knowledge of the various medical treatment possibilities that they were able to self-regulate their medication according to their circumstances: C18 'I told the physician to teach me how to do it with cortisone, and now it's me who increases or reduces the dose'; C06 'When I need to go out, I take a couple of anti-diarrheic pills and then I'm ready to go: I know that they do me no harm'; C01 'There are moments when I stop taking my pills because they're not doing anything, and later I start taking them again'.

Similarly, they were experts on the adequate diet and knew exactly what sort of food to eat and which one to avoid. This enabled them to manage their diet according to their individual circumstances, in terms of not only intake but also cooking methods: C06 'I already know what I can and cannot eat, to be well; for example, I can't drink milk, and I have to eat meat together with bread in order to avoid diarrhea'; C17 'I can't eat fried food, so all my food is boiled or grilled'; C15 'I have to be very careful about what I eat outside my home, so I usually take home-made food with me'.

**Table 3** Emergent themes and theme clusters

Emergent themes	Theme clusters
1. Self-protection against the unknown cause	1. CD management 2. Lack of confidence in the health system
2. Self-training	3. Cause-effect 4. Self-control
3. Learning to live with CD	5. Normalisation of the condition 6. Ignoring chronic illness 7. Expertise management
4. Perceived losses due to CD	8. Limitations 9. My other self
5. Relationships with others	10. Family and friends 11. Other people with CD 12. Healthcare professionals

Additionally, extraordinary emotional control was detected, because although the word 'depression' appeared in almost all the narrative accounts, participants were able to overcome this without psychological help: C16 'Well, I think I had something like depression, but it passed'; C05 'It's not that I sank into depression, but it was something like that, but you have to see things from another perspective or you'd always be down'.

#### Theme 4. Perceived losses due to CD

*Limitations.* However, not everything seemed positive: participants also perceived several limitations as losses in their lives. These included barriers to certain jobs or academic qualifications: C14 'Well, I struggled to find a job that I could balance with Crohn's disease because I couldn't work a full shift and I also needed a toilet nearby'; C02 'In the end, I settled for a diploma and didn't try for a degree because my health suffered whenever I had exams'. Another limitation emerged in the crosscutting theme cluster of parenthood ('Family and Friends'). Most participants were parents, but they had had to give up the idea of having more children because of the difficulties experienced with the first child during pregnancy and subsequent care. Female participants had experienced complications during pregnancy: C09 'Having Nico was really hard for us, I spent six months in hospital, we practically lived there, and I even had to have an operation while pregnant. So having another one is out of any consideration for me'; C05 'I would have liked to have more children, but I can hardly take care of one, so I decided not to have more'. Leisure also appeared to be restricted because participants had to limit their outings only to contexts where they felt 'protected': C01 'I don't usually go out, except to my sister's house, but not to other places'; C13 'For example, I've stopped going to the cinema or to the countryside, in case I suddenly need to go to the bathroom... I don't want to be a nuisance'. The interviewees' accounts also revealed a tacit sense of shame associated

with the potentially social stigma attached to the symptoms of the disease, such as bowel urgency or abdominal bloating: C12 'If you go out to eat and have to leave the table a lot, people start to wonder... so I'd rather just stay at home'; C03 'I haven't said this before but it's true that sometimes my stomach makes funny noises and the other people in the office look at me as if to say "What on earth's wrong with him?"; C06 'When I have to use the bathroom in the house of someone who is not a member of my family, I worry that the people there are thinking "look at him, coming to my house to constantly use my WC", so I look for other alternatives because I don't want people to think I'm dirty or weird'.

*My other self.* Participants explicitly talked about the loss of their 'self' prior to learning about the disease. Most felt they were unrecognisably different now to the person they had been before. Somewhat wistfully, they recalled that before having CD, they were always laughing and joking, did not think twice about things and were game for anything. They also reported losses in their relationships with others, as they now described themselves as impatient, subject to mood swings and easily irritated: C17 'I used to be happier, I was always laughing, but now I'm always thinking about the disease, whether I'm about to have a flare-up, or controlling pain; in the end, living with constant pain takes its toll and you become more serious'; C03 'I wasn't afraid of anything before and I did loads of things, now I think carefully before doing anything and when I have to do something, I think it over so much that I end up not doing it'; C06 'I don't know, I'm grumpier now...'.

#### Theme 5. Relationships with others

*Family and friends.* All participants mentioned support from those around them in their narrative accounts: C06 'My parents and my girlfriend are the crutches I lean on when I'm limping'. Their most immediate circle (parents, partner and friends) gave them the crucial support they needed to be able to cope with the disease and lead a life as similar as possible to the one they had before the condition appeared: C16 'My husband has always stood by me, I don't know what I would do without him, and my friends too, who have always come to visit me when I've been in hospital'. Their support networks not only were an important part of participants' lives when they were in hospital but were also essential for many of their everyday tasks: C02 'Thank goodness my wife dressed my bag wound, because I couldn't have done it'; C11 'My husband did the cooking and the cleaning, and always kept my spirit up, because I only had enough strength for my job and nothing else'. Sometimes, participants reported feeling that they were themselves a burden, and that they tried to compensate those feelings in remission periods: C14 'Sometimes I do think I'm a burden, because I can't do much and they have to help me so I can carry on, but when I'm well I help in every way I can'.

*Other people with CD.* Participants also reported feeling supported by other people with CD but rejected the idea of associations in the beginning, preferring to meet others like themselves face to face or via social networks, although not actively but rather in pursuit of information: C19 'I never wanted to go to the association, there are only people worse than me there, but I do go to talks when I hear that an expert is coming to speak about the topic'; C05 'I look at information uploaded onto Facebook and I talk a lot with the others when we meet at the day hospital for treatment'.

*Healthcare professionals.* Participants reported feeling complete confidence in the person who diagnosed them, since this represented an answer that put an end to a never-ending ongoing of medical tests and false diagnoses. Indeed, the relationship with that professional could be described as a personal one and almost of friendship: C10 'I don't have to make an appointment with the physician; when I'm feeling ill, all I have to do is to go to his office'; C03 'Thank God I stumbled upon this doctor, who even came to see me on her days off to see how I was'. However, as time passed and the participants became more and more aware of their new condition and eager to learn more about their disease, their opinions started to change about the professional staff and they began to demand more attention, more cares and above all more information, as a result of their experience: C17 'I tell my physician to prescribe me something to make me feel better, but he says that there is nothing else, although I think there is'; C18 'He only cares about the symptoms, he doesn't ask how I am or at least if anything has changed in my day to day life, all he does is to look at the test results and supervise my medication'. Consequently, once they considered themselves experts on CD, they preferred professionals who gave them what they needed, such as a quick admission to the hospital, useful advices or prescriptions without prior tests, as do the nurse: C09 'For me, the nurse at the day hospital was the best, because I would call her and say, such and such is wrong with me, and she would immediately arrange for me to see the doctor or have the tests I needed to confirm my suspicions'.

## Discussion

Despite the increasing number of studies that focus on patients' perspectives (6, 10, 19, 25, 26), it still appears that little importance is given to this disease maybe due to the unseen nature of this chronic condition, and as it does not cause a manifest inability to perform basic activities of daily living, and thus remains invisible in today's society.

This study evidences that having a chronic disease changes the way one understands life as it involves entering other worlds that were previously seen as alien

(13, 27, 28). Our results demonstrate that people yearn for the person they had been before, in some way being obliged to learn to construct and live with a new identity entailing consequently a loss of 'self'. This involves not only the people with CD but also their families and social networks, disrupting the rules of interaction established as normal (29).

As stated by other authors, we outline that the insidious onset of this CD, its appearance at an early age, its links with autoimmunity and the lack of knowledge about its causes as well as the way to face it altogether lead the affected ones to perceive a lack of information from the time of the onset onwards (19, 30). Consequently, people with CD constantly seek information, since the one provided by the healthcare team does not seem sufficient (31, 32). In addition, people with CD are obliged to learn from the experiences and discoveries acquired through constant trials and errors since their diagnosis, and to become self-trained experts.

Due to the characteristic symptoms of this disease, such as bowel urgency, one of the greatest concerns of those affected is the loss of control over their own body (26, 33) as it has been evidenced previously by scientific literature. In line with this, they may even feel a level of rejection from the general population, provoked by the stigma associated with a disease considered as dirty because it involves body wastes (34, 35).

Consequently, people with CD develop personal strategies to render the problems associated with the disease compatible with their daily routines. This study reveals that such strategies include developing a heightened awareness of bathroom access possibilities, adopting dietary changes and rationing energy to control fatigue, a symptom associated with this disease that, as other studies have shown (7, 34, 36, 37), determines a customary aspect of the condition, although recent studies on CD have not mentioned it as an associated symptom (38).

In agreement with our results, several studies have reported that people with CD demonstrate a positive attitude and a struggling spirit (10, 16). Concretely one key strategy that merged in our sample was to normalise the illness, ignoring it to the point of downplaying the symptoms and assuming them as simply another aspect of life.

According to other studies (39, 40), our results indicate that despite their various coping strategies, people with CD experience difficulties in reconciling professional and social life with the disease, in their intimate relationships and even in their possibility of being parents (41, 42).

Our study confirms what the literature previously stated about social support, considered as a protective factor in chronic disease, and therefore as a mitigating factor during CD flare-ups (43–45). We also show similarities with those studies evidencing that the support received from those currently near them, such as family and friends, enables people with CD to maintain a similar life

to the one that they would have led if they had not developed the disease (46, 47).

Furthermore, participants did not have a positive opinion of CD professional supervision as it was also stated by other authors regarding inflammatory bowel disease (48) and even evinced a perception of abandonment, reporting that they were included in various nonspecific programmes that merely addressed their symptoms while neglecting how they understood and coped with the illness. It was surprising, however, that our participants did not wish to be actively involved in an association, since CD is a condition that before has low visibility in the health system of the context explored. With regard to perceived support from health professionals, participants were only satisfied at the time of diagnosis and with professionals who facilitated the various administrative procedures necessary for arranging hospital admission, tests or medical appointments.

#### *Study limitations*

Although the data analysed in this study reflect on the lived experiences of a specific group of people with Crohn's disease in a concrete geographical setting such as the province of Alicante (Spain), the sample selected was considered heterogeneous and representative to some extent mapping the most typical CD profiles in the context selected. Obviously, factors related to the cultural characteristics of the sample as well as those organisational ones associated to the particular health system are part of the qualitative essence of this study. Thus, given the qualitative methodology employed, it is not possible to extrapolate the data reached to other contexts that do not share similar characteristics. Understanding the experience of those affected by CD in a concrete context from an experiential learning perspective, far from global generalisations, provides researchers and professional workforce with useful information to make concrete decisions about the issues identified as weaknesses of the health systems and patients' perceived needs.

#### **Conclusion**

The qualitative nature of this study provides the 'voice' of people with CD, which is often lacking in the literature, thus providing healthcare professionals with insight into the perceptions and experiences of those affected. The inability to understand the experiences of individuals with chronic conditions such as CD can act as a barrier in the treatment and interaction/rappport between healthcare professional and client.

This study shows that CD affects people's lives, becoming a breakdown since the diagnosis is revealed,

limiting their day-to-day activities, and above all implying crucial changes that those affected must overcome. People with CD must learn to live with a chronic condition that interferes within all aspects of their lives, and must therefore learn to cope with this. They become thus in people who are not socially perceived as chronic patients, as they constantly struggle with changes towards keeping the new chronic condition as invisible to the others' eyes since the early ages at which it is usually diagnosed and probably encouraged by the desire to be like the rest. People with CD wish to be the way they were before though sometimes having a sense of loneliness. They are considered as independent patients who could be defined as unseen hostages that experience uncertainty and lack of knowledge and professional support from the beginning.

Moreover, the importance of the peer-to-peer support, coming from other people with CD or from social networks, perceived as equals that seems to ease the burden of chronic illness, is demonstrated. The present study elucidated the lack of CD specific organisations and clinical pathways within the health system of the sample explored as well as the lack of trained professional workforce regarding CD. Furthermore, social support merged as a bullet point to be considered for future improvements in the CD people adaptation process, especially in family-centred cultures such as the Spanish one.

Our results thus highlight the need to professionally assess and study in depth and comprehensively the various treatments available as well as the real needs of people with CD in order to implement caring interventions based on those affected' experiential learning and testimonies towards improving their transition and adaptation process from the beginning, especially in those health systems in which less attention has been paid to CD.

#### **Author contributions**

All authors took part in the conception, design and analysis of data. In addition, data collection was carried out by Sofía García-Sanjuán, drafting of the manuscript by Sofía García-Sanjuán and Manuel Lillo-Crespo and critical revisions for important intellectual content by Ángela Sanjuán Quiles and Miguel Richart Martínez. All authors have agreed on the final version of the manuscript.

#### **Ethical approval**

This study was approved by the Ethics Committee of the Research Office at the University of Alicante file number: UA-2016-06-20.

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